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ABSTRACT

The booklet provides information on current family-oriented research activities based on a survey of 16 Rehabilitation Research and Training Centers and 17 projects funded by the National Institute on Disability Research or other agencies. Information provided for each center includes name, address, phone number, director, funding source and period, a brief description of the center, brief descriptions of each of the center's projects, and a listing of center and project publications. Centers are listed alphabetically by state; projects connected with universities alphabetically by name of the university; and miscellaneous projects alphabetically. A feedback sheet is provided to encourage additional or corrected information for further editions. (DB)

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Call to the Field:
Research on Families and Disability
1988-1989

May 1989

Prepared by:
Harriet Shaffer
Julie Cross

Prepared under a grant from the National Institute on
Disability and Rehabilitation Research

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The University of Kansas
Bureau of Child Research
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Lawrence, KS 66045

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INTRODUCTION

WHAT IS THE PURPOSE OF THIS BOOKLET?

In this booklet, we at the Beach Center on Families and Disability provide you with information about family-oriented research activities nationwide. This information has been reported to us in response to our Center's "Call to the Field" to 38 Rehabilitation Research and Training Centers, and 92 other projects primarily funded by the National Institute on Disability Research, as well as some funded by other agencies. In addition, some responses were received in response to a mailing about a conference on value-based family research held by the Beach Center for Families and Disability, May 5 - 7, 1989, in Washington, D.C. Responses were received from 16 Research and Training Centers and 17 other projects. Our purpose is to provide you with this information as a means of establishing an information exchange and as a way of establishing collaborative networking among researchers with interests in families and disabilities. Since the Beach Center on Families and Disability has as its main emphasis the effects of disability on the family, we see one of our missions as that of providing information to researchers nationwide about work being done in relation to families and disability.

WHAT IS FAMILY RESEARCH?

By "research on families and disability" we are referring to basic, applied, or policy research that investigates variables related either to the family as a whole or to a relative (e.g., parent, spouse, sibling) of a person with a disability. We are not including research related to an individual with a disability per se, unless that research is focusing on some aspect of the person's interactions with his or her family. We define a family member as anyone related by blood, marriage, adoption, foster-family status or long-term association.

HOW IS THIS MATERIAL ORGANIZED?

We want to make it clear that we are using information provided to us by the particular project in response to our "Call to the Field". Thus, we are including only information from projects that responded to our request. We plan for this booklet to be a publication of our Center in 1989, 1991, and 1993; thus, we plan in future years for the number of projects described to increase. If you receive this booklet and information about your Center or project is not included and you would like it to be included in the future, please let us know so that we can contact you next year. We hope that this booklet is of use to you; we welcome your input and feedback and have included a feedback page for your use. Please let us know if we have not described your project or Center correctly. In most cases, we used the description provided by your Center or project; if there was no such description, we used the description of the Center or project provided in the NARRTC Directory (1988) or the NIDRR Directory (1989). We appreciate the feedback we received on our "Call to the Field" letter; that feedback will help us to be more specific in our requests next year.

We are providing descriptive information about each project. In addition, many Centers and projects mailed us copies of publications as well as copies of research instruments. Thus, we are including information on published materials (i.e., specific citations) as well as information on materials published by the particular Center or project. Here again, we included information about publications only if copies of the publications were mailed to us.

You may contact the project directly at the address or phone number provided if you wish further information about a particular Center, project, or publication.

Spain Rehabilitation Center

Rehabilitation Research & Training Center in the Prevention and Treatment of
Spinal Cord Injury
University of Alabama
University Station, 1717 6th Ave., S.
Birmingham, AL 35294
(205) 934-3334

Project Director: Samuel L. Stover, M.D.
Research Director: J. Scott Richards, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 6/88 - 5/93

Center Description

The goal of the Center is to improve rehabilitation management of persons with spinal cord injury. The Center conducts basic and clinical research into new methods and techniques to prevent and treat complications occurring in persons with spinal cord injury.

Project Name

Medical and Psychological Considerations Regarding the Surgical or
Pharmacological Treatment of Impotence in Males with SCI

Project Description

People with SCI seeking treatment for sexual dysfunction will be offered either a penile implant or injections to try & improve erectile function. This study, using tests of sexual behavior and satisfaction, will determine if these options are helpful and are worth the associated risks.

Project Name

A Longitudinal and Cross-Sectional Analysis of Well-Being in Persons with
Spinal Cord Injury and Their Caregivers

Project Description

This study will examine the quality of life for both people with SCI and their primary caregivers at several intervals post-injury.

Project Name

Outcomes of Post-Spinal Cord Injury Marriages

Project Description

This study followed 410 persons injured since 1973 and enrolled in the National Spinal Cord Injury Statistical Center data base who get married after their injury. Results suggest that the impact of SCI on post-injury marriages is almost as substantial as it is on pre-existing marriages.

**Spain Rehabilitation Center:
Rehabilitation Research & Training Center in the Prevention and Treatment
of Spinal Cord Injury**

Publications:

1. DeViro, M., & Fine, P. (1985). Spinal cord injury: Its short-term impact on marital status. Arch Phys Med Rehabil, 66, 501-504.
2. Lopiccolo, J. & Steger, J. (1975). Sexual interaction inventory. Archives of Sexual Behavior, 3(6), 585-595.

Center Publication:

1. A Guide to Developing Educational Conferences for Families of People with SCI (6/89 - 5/90)
2. What is SCI? An Elementary Overview (6/89 - 5/91)
3. A Handbook of Self-Care for People with SCI (6/89 - 5/91)
4. Preventing Secondary Complications: Do's and Don'ts for Personal Care Attendants of People with SCI (6/90 - 5/91)
5. Research Update for People with SCI (6/90 - 12/92)
6. Research Update: Annual Review (6/88 - 5/93)
7. Educational Materials Catalog (6/88 - 5/93)
8. Consumer Newsletter: Pushin' On (6/88 - 5/93)
9. Richards, J. S., & Jaworski, T. (1988). Family Adjustment To Spinal Cord Injury, The University of Alabama at Birmingham. Grant # G008300053
10. UPDATE: SPINAL CORD INJURY Brochure, Rehabilitation Research & Training Center in Spinal Cord Dysfunction At Spain Rehabilitation Center, The University of Alabama at Birmingham.

American Indian Rehabilitation Research & Training Center

Northern Arizona University, Inst. for Human Development
Box 5630
Flagstaff, AZ 86011-5630
(602) 523-4791

Project Director: Charlotte Tsoi Goodluck, MSW
Research Director: William E. Martin Jr., Ed.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 1988-1993

Center Description

The Center conducts research and training that supports rehabilitation and special education services for American Indians. Projects include those in the areas of: (a) job development on and near reservations using local labor market analyses and model job training programs, (b) investigation of culturally sensitive rehabilitation strategies, (c) community systems analyses through consumer involvement and (d) investigation of specific types of disabilities that are of significant concern to American Indian people.

Project Name

Utilization of Genograms and Eco-maps to Assess American Indian Families Who Have a Member with a Disability (Making Visible the Invisible)

Project Description

This project will investigate the utility of the genogram & eco-map as family assessment tools for working with American Indian VR clients referred for disability services & to describe changes in the family after VR services by evaluating information in the genogram and eco-maps at the beginning and end of the service.

American Indian Rehabilitation Research & Training Center

Center Publications:

1. Utilization of Genograms and Eco-maps to Access American Indian Families who have a Member with a Disability (Project R-18)

Rehabilitation Research & Training Center in Progressive Neuromuscular Diseases

Univ. of California, Dept. of Physical Med. & Rehab.
T8191 School of Medicine
Davis, CA 95616
(916) 752-2903

Project Director: W.M. Fowler, Jr., M.D.
Research Director: Richard K. Enrikin, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 3/1/88 - 2/28/93

Center Description

The Center conducts a broad-based, multidisciplinary program of research in the area of comprehensive rehabilitation management of neuromuscular diseases. It initiates training that transposes research findings into tangible products that rehabilitation practitioners and educators can use in service delivery and teaching programs. The goal of all research projects is to identify factors that prevent or limit successful rehabilitation and to develop intervention strategies to overcome those limiting factors.

Project Name
Student Education Questionnaire

Project Description

Summer camp attendees participated in a pilot assessment of educational needs. A questionnaire to survey parents' impressions of the educational system is in preparation.

Project Name
Development of Rehab. Options to Improve Vocational, Educational and Independent Living Options in Progressive Neuromuscular Diseases

Project Description

No description provided.

Rehabilitation Research & Training Center in Progressive Neuromuscular Diseases

Center Publications:

1. Neuromuscular Disease: Patient Education Program, (Grant No. G008300078) April 25, 1987, flyer
2. MDA NEWS AND REVIEW: Official Newsletter of MDA's Greater Northern CA Chapter, (1988).

Pediatric Research & Training Center

Univ. of Connecticut Health Center/ Child & Family Studies
The Exchange
Farmington, CT 06032
(203) 674-1485

Project Director: Mary Beth Bruder, Ph.D.
Research Director: Gerald Mahoney

Funding Agency: U.S. Department of Education, Office of Special Education
Funding Period: 4/84 - 4/89

Center Description

The Center is dedicated to the habilitation and rehabilitation of all children with disabilities with special emphasis on birth-to-five. Research and training activities of the Center focus on family services and community-based programs. The Center addresses the needs of the target population through community-identified initiatives and the development of strong working relationships with state and private resource organizations.

Project Name

Interactions between mothers and their handicapped children: A longitudinal study

Project Description

This investigation was conducted to identify patterns of material communication with young children with mental retardation and to determine how these patterns of the mother relate to the communicative competence of the child.

Project Name

A National Study of the Practices of Early Intervention Service Providers

Project Description

This is a study of almost 1000 professionals from six states who were working in intervention programs from birth to six year old children with disabilities and their families to gain the perspective of these service providers.

Project Name

Maternal Perceptions of Family Focused Early Intervention Services

Project Description

A questionnaire was completed by a sample of 503 mothers of birth to 6-yr old children with disabilities enrolled in intervention programs throughout the U.S. The questionnaire was designed to identify types of family intervention services mothers were currently receiving and the types they would like to obtain.

Pediatric Research & Training Center

Publications:

1. Mahoney, G. (1988). Maternal Communication Style With Mentally Retarded Children. American Journal on Mental Retardation, 92(4), 352-359.
2. Mahoney, G. (in press). Communication Patterns Between Mothers and Mentally Retarded Infants, First Language.
3. Mahoney, G., Finger, I., Powell, A. (1985). Relationship of maternal behavioral style to the development of organically impaired mentally retarded infants. American Journal of Mental Deficiency, 90,(3), 296-302.
4. Mahoney, G., O'Sullivan P., Fors, S. (in press). The family practices of service providers for young handicapped children. Journal of Infant Mental Health.
5. Mahoney, G. & Powell, A. (1986). The Maternal Behavior Rating Scale, Topics in Early Childhood Special Education, 6(2), 44-55.
6. Mahoney, G., Powell, A. (1988). Modifying parent-child interaction: Enhancing the development of handicapped children. The Journal of Special Education, 22(1), 82-96.
7. Marfo, K. (1988). Parent-child interaction and developmental disabilities. New York: Praeger.
8. O'Sullivan, P. & Mahoney, G. (1989). Early intervention practices with families of handicapped children, Mental Retardation.

Center Publications:

9. Mahoney, G. and O'Sullivan, P. (1988). A National Study of the Practices of Early Intervention Service Providers. (Monograph, No. 10) Farmington, CT: Pediatric Research & Training Center.
10. Mahoney, G., O'Sullivan, P. & Dennenbaum, J. (1989). Maternal Perceptions of Family Focused Early Intervention Services. (Monograph, No. 11) Farmington, CT: Pediatric Research & Training Center.

Research and Training Center for Children's Mental Health

Florida Mental Health Institute

University of South Florida
13301 Bruce B. Downs Boulevard
Tampa, FL 33612-3899
(813) 974-4500

Project Director: Robert M. Friedman, Ph.D.
Research Director: Starr Silver, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 9/84 - 9/89

Center Description

The purpose of the Center is to increase the knowledge base for development and delivery of services for children with serious emotional disabilities (SED) and to enhance the use of existing knowledge to strengthen services for children with serious emotional disabilities. The Center's initial activities focus on research, study of systems of service, review of strategies for evaluating children's mental health programs, and a study of advocacy approaches.

Project Name

NACTS, National Adolescent & Child Treatment Survey

Project Description

The NACTS is a nationwide, four-year, sequential cohort study of 960 children with serious emotional problems. Goals of the study are to describe the characteristics and problems of the children and their families, determine the types of services they receive, and describe how the problems and services change over time.

Research & Training Center for Children's Mental Health

Center Publications:

1. Annotated Bibliography- describes material prepared by staff of Florida Mental Health Institute, University of South Florida.
2. Family Functioning and Psychopathology Among SED Adolescents-Draft
3. "The Diagnostic Interview Schedule For Children: A Study of Its Utility with Children and Adolescents Identified as Emotionally Disturbed by Mental Health and Special Education Systems" (1988)
4. "Characteristics of Children with Serious Emotional Disturbances Identified by Public Systems as Requiring Services" (1988)
5. National Adolescent and Child Treatment Survey, Parent Interview

Pacific Basin Rehabilitation Research & Training Center

John A. Burns School of Medicine
266 North Kuakini Street
Honolulu, HI 96817
(808) 537-5986

Project Director: Daniel D. Anderson, Ed.D.
Research Director: Joyce M. Varney, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 3/89 - 3/94

Center Description

The goal is to improve services provided to persons with disabilities through rehab. research and training in the Pacific Basin and to assist in the coordination of medical, educational, and vocational rehabilitation services. Objectives are to develop a sound demographic base, collect and analyze data on incidence and prevalence of disability, develop culturally relevant rehabilitation programs using appropriate technology, and assess rehabilitation personnel needs for manpower training.

Project Name

Assessment of Individual Functioning, Care Providers and Customary Environment

Project Description

We are considering the total context in which individuals with disabilities operate, as well as attitudes, skills and knowledge of their care provider(s) and important aspects of their physical home and work environments.

Pacific Basin Rehabilitation Research & Training Center

Center Publications:

No publications were directly provided to the Beach Center.

Beach Center on Families and Disability

Bureau of Child Research

The University of Kansas
4138 Haworth Hall
Lawrence, KS 66045
(913) 864-7600

Project Director: Ann P. Turnbull, Ed.D.; H.R. Turnbull, III, LL.M.
Research Director:

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 1988-1993

Center Description

The Beach Center's primary concerns in its research, dissemination and training activities are those of families with a member with a disability. The Beach Center believes that persons with disabilities contribute positively to their families, that families should have great expectations for the future, that persons with disabilities are entitled to full citizenship, that families should have choices, that relationships are crucial to family unity, and that families have inherent strengths.

Project Name

Assessment of Strengths and Needs in Families with Children with Developmental Disabilities

Project Description

The purposes of this research are to 1) identify family & provider opinions concerning preferred processes to incorporate state-of-the-art values into the process for developing IFSPs & identify expected outcomes for families of early intervention; 2) design & investigate a model procedure for developing IFSPs that combines preferences & opinions.

Project Name

Permanency Planning: A One-Year Planning Study

Project Description

The purpose of this project was to plan the research agenda for future activities. Staff members have carried out that purpose by conducting a literature review, meeting with consultants, developing a proposed two-pronged research plan on reasonable efforts, and developing drafts of recommendations for policy reform.

Project Name

Assisting Families of Participants in Adult Day Care

Project Description

This project is based on 2 reviews of caregiving research with the objective of providing an overview of 'what works' to assist caregivers, and also to point to promising practices that are in the process of being developed or might be developed.

Beach Center on Families and Disability

Project Name

An Evaluation of Family Decisions to Provide Home-Based vs. Hospital-Based Care for Technology Dependent Children

Project Description

This research has resulted in an extensive literature review concerning children who are supported by technology and their families, a draft of an article for school administrators about the placement of such children in regular settings, a draft of an article for school nurses about the education of these children, and a plan for research on family-school interactions related to the educational outcomes for these children and the provision of related services in regular education settings.

Project Name

Research on Behavior Assessment & Behavioral Intervention in Competence in Decision-Making by the Adolescent/Adult with a Disability: Expression of Preference by Adolescent/Adult with a Disability and/or Other Members of the Family

Project Description

The purpose of this research is to develop a model and an assessment system based on the model that will allow a family or a family support worker to identify positive and negative experiences resulting from the presence of the adolescent/adult with a disability in the family structure. In addition, the assessment system will determine the way families respond to these positive and negative experiences. This will be followed by the design of specific interventions intended to result in increasing or at least ensuring the maintenance of positive experiences and decreasing or at least reducing the intensity of negative experiences.

Project Name

Research on Behavioral Assessment and Behavioral Interventions in
(A) Competence in Decision-Making by the Adolescent/Adult with a Disability;
(B) Expression of Preferences by Adolescent/Adult with a Disability and/or
Other Members of the Family

Project Description

The purpose of this research is to evaluate competency assessment and expression of preference as two aspects of the future planning model developed by Turnbull, Turnbull, Bronicki, Summers, and Roeder-Gordon (1989). This model encourages planning that, to the greatest extent possible, is based on the choices and preferences of the person with the disability but also considers the needs of the whole family and involves current and potential service providers, supporters, and anyone else who has an interest in the family member with a disability.

Beach Center on Families and Disability

Project Name

**Research on Qualitative Assessment of the Impact on the
Members of a Social Fraternity of Being Hosts to a Young Man
with Developmental Disabilities**

Project Description

Using the pentad inquiry structure, the purpose of the proposed study is to learn about facilitators by conducting and interpreting interviews with reference to: Who would facilitate in the social life of a person with mental retardation? What (and how) do they facilitate within that individual's social lifestyle? Why, when and where are those facilitating functions performed?

Project Name

**The Family Enhancement Program: The Development and
Evaluation of a Multi-Component Family Treatment Program**

Project Description

The goal is to develop, implement, and evaluate an in-home, multi-component family treatment program for families of adolescents with emotional disorders. The ultimate purpose is to do research that helps families remain as integral units with optimum methods of functioning, help prevent out-of-home placement of youths with severe disturbance, and help build social skill competencies for all family members.

Project Name

Cognitive Adaptations Interventions Strategies

Project Description

The purpose of this research is to examine the effectiveness of interventions designed to increase the use of cognitive adaptations coping strategies. Specific research questions are whether the frequency of use of coping strategies increases after intervention and whether increased frequency of use of coping strategies is associated with decreased stress or improved family well-being?

Project Name

**Plan and Conduct a National Survey and Impact Study
of the Parent to Parent Support Programs**

Project Description

The purpose of the Parent to Parent National Survey Project is to gather information about the Parent to Parent network as a first step toward developing an empirically based evaluation of Parent to Parent programs. Because the number of programs utilizing a Parent to Parent model as a component of the services provided is unknown, as is the effectiveness of the model on a broad scale, in order to fully understand the scope of the network and the success of the approach, there is a need to collect descriptive data.

Beach Center on Families and Disability

Project Name

The Protection and Advocacy for Mentally Ill Individuals Act of 1986
(P.L. 99-319): A Policy Analysis of Implementation Process with Respect to
the Desinstitutionalization of Children with Severe Emotional Disabilities

Project Description

The purpose of the research was to study the implementation of P.L. 99-319
with respect to the goal of deinstitutionalization of children with emotional
disabilities.

Beach Center on Families and Disability

Center Publications:

1. Brochure, Beach Center on Families & Disability
2. Newsletter, Families & Disability, (3 times annually, first issue 5/89)
3. Publications Catalog, 6/89
4. Turnbull, A.P. & Turnbull, H.R. (1988). Families and Community Integration. Syracuse University Forum on Community Integration.

Publications:

1. Brother, M., Turnbull, A., Bronicki, G., Houghton, J., Roeder-Gordon, C., & Turnbull, H. (September, 1988). Transition into adulthood: Parental planning. ETMR.
2. Petr, C. (in press). Protection and advocacy for the mentally ill: New hope for emotionally disturbed children. Community Mental Health Journal.
3. Turnbull, H.R., Guess, D., & Turnbull, A.P. (1988). Vox populi and Baby Doe. Mental Retardation, 26(3), 127-132.
4. Turnbull, A.P. & Turnbull, H.R. (1988). Toward great expectations for vocational opportunities: Family-professional partnerships. Mental Retardation, 26(6), 337-342.
5. Turnbull, A.P., Turnbull, H.R., & others. (1986). Families, professionals, and exceptionality: A special partnership. Columbus, OH: Charles E. Merrill Publishing Company.
6. Turnbull, H.R., & Turnbull, A.P. (Eds.) (1985). Parents speak out: Then and now. Columbus, OH: Charles E. Merrill Publishing Company.
7. Turnbull, H.R., Turnbull, A.P., Bronicki, G.J., Summers, J.A., & Roeder-Gordon, C. (1989). Disability and the family: A guide to decisions for adulthood. Baltimore: Paul H. Brooks Publishing Company.

Research & Training Center in Childhood Trauma & Rehabilitation

New England Medical Center
750 Washington Street, Box 75K-R
Boston, MA 02111
(617) 956-5622

Project Director: Bruce Gans, M.D.
Research Director: Stephen Haley, Ph.D., P.T.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 1988 - 1992

Center Description

Childhood injury is a largely unknown disorder, yet trauma is the leading cause of death and disability in children. The Tufts-NEMC RTC is developing and disseminating an information base that describes the natural history of childhood trauma and its consequences. Methods of identifying and measuring the benefits of specific intervention strategies are being developed.

Project Name

Pediatric Evaluation of Disability Inventory

Project Description

This is a pilot study with the purpose of establishing reliability and validity in year 1, and of standardizing the instrument on 700 children without disabilities in year 2.

Research and Training Center in Childhood Trauma and Rehabilitation

Center Publications:

1. Haley, S., Gans, B., Webster, H., & Faas, R. (1988). (PEDI)
Parental Report/Self-Administered Version
2. Pediatric Evaluation of Disability Inventory (Versions-Draft 10,
Draft 2)

Research & Training Center for the Psychiatrically Disabled

Psychiatric Institute

Albert Einstein College of Medicine
722 W 168th Street/ Box 111, Rm. 212
New York, NY 10032
(212) 960-2554

Project Director: William McFarlane, M.D.
Research Director: William McFarlane, M.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 9/30/85 - 9/29/90

Center Description

The focus of the Center is to improve and maintain the rehabilitation of individuals with psychiatric disabilities. The program consists of interrelated research and training projects in three areas: vocational rehabilitation outcomes; development of standardized disability determinations; and rehabilitation interventions in the home, community and criminal justice system.

Project Name

Psychoeducational Multiple Family Intervention for Schizophrenia in the Altro
Vocational Rehabilitation Setting

Project Description

The goal of this project is to test a psychosocial intervention for schizophrenia in the Altro Health & Rehabilitation Services. This project involves a family psychoeducational approach.

Research & Training Center for the Psychiatrically Disabled
Center Publications:

No publications were directly provided to the Beach Center.

Rehabilitation Research & Training Center on Community Integration of
Persons with Traumatic Brain Injury

State University of New York at Buffalo
197 Farber Hall, 4434 Main Street
Buffalo, NY 14214
(716) 831-2300

Project Director: John H. Noble, Ph.D. & Barry S. Willer, Ph.D.
Research Director: William C. Mann, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: No dates provided.

Center Description

The Center conducts: 1) studies relating to effective mechanisms of community integration and 2) a training and information dissemination program for professionals and families of persons with traumatic brain injury (TBI). The Center seeks to empower consumers, families, and TBI advocacy organizations.

Project Name

Model Family-Professional Partnership Interventions for Childhood Traumatic
Brain Injury Survivors

Project Description

This project addresses the social, psychological & economic impact of traumatic brain injury on families of children up to age 16 by developing & evaluating techniques for family involvement in the treatment, education, &/or rehabilitation process with incentives & disincentives to family involvement. (With the NY State Head Injury Assoc.)

Rehabilitation Research and Training Center on Community Integration of
Persons with Traumatic Brain Injury

Center Publications:

1. Brochure on RRTC on TBI.
2. Seminar information- The Management of Behavioral Sequelae of
Traumatic Brain Injury, Hyatt Regency Hotel at Crystal City,
Arlington, Virginia (March, 1989)

Rehabilitation Research & Training Center to Improve Services for Seriously
Emotionally Handicapped Children & Their Families
Regional Research Institute

Portland State University
P.O. Box 751
Portland, OR 97207-0751
(503) 464-4040

Project Director: Barbara J. Friesen, Ph.D.
Research Director: Richard Vosler-Hunter, M.S.W.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 10/84 - 9/89

Center Description

The Center's purpose is to conduct research on ways of improving services to help children with emotional disturbances live at home, learn in school, and succeed at paid employment; to develop training materials and programs for professionals, parents, and employers; and to serve as a resource center for other individuals and organizations working on behalf of children with emotional disabilities and their families.

Project Name

Survey of Parents of Children with Emotional Handicaps

Project Description

This survey was designed to gather information about parents' needs, experiences with obtaining services and needed information, sources of support and effects on family life.

**Families as Allies, Research & Training Center to Improve Services to
Seriously Emotionally Handicapped Children & Their Families**

Center Publications:

1. Parent Survey (1987)
2. Taking charge: A Handbook for Parents (1987-88)
3. Parent Organization Directory (1986)
4. Focal Point (newsletter, 4 issues annually)
5. Annotated Bibliography on Therapeutic Methods (1988)
6. Annotated Bibliography on Child Advocacy (1986)

ILRU Research and Training Center on Independent Living at TIRR

The Institute on Rehabilitation and Research
3400 Bissonnet, Suite 101
Houston, TX 77005
(713) 666-6244

Project Director: Margaret A. Nosek, Ph.D.
Research Director: Margaret A. Nosek, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 1985 - 1990

Center Description

The purpose of the Center is to promote the independence of persons with disabilities through research, training, and technical assistance activities focused on service providers.

Project Name

Study of Personal Assistance Service for Persons with Severe Disabilities

Project Description

This will examine existing types of helping systems and attempt to reach a new understanding about how the adequacy of personal assistance services determines functioning and quality of life of persons with severe disabilities and how their need for those services can best be met.

ILRU Research and Training Center on Independent Living at TIRR
Center Publications:

No publications were directly provided to the Beach Center.

Rehabilitation Research & Training Center in Community-Oriented Services for
Persons With Spinal Cord Injury

Baylor College of Medicine
1333 Moursund Avenue
Houston, TX 77030-3405
(713) 960-1233

Project Director: Diana Hopkins Rintala, Ph.D.
Research Director: Marcus J. Fuhrer, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 1/1/88 - 12/31/92

Center Description

The Center conducts a coordinated program of research, training, and service demonstrations that has the goal of improving the health maintenance, psychological adjustment, and community integration of persons with spinal cord injury who have resumed their lives in the community after receiving acute rehabilitation services. A corollary goal of the Center is to develop further understanding of the aging process of persons with spinal cord injury.

Project Name

The Influence of Caregiver Well-Being on Outcomes for Persons with Spinal Cord Injury

Project Description

This study will cross-validate previous findings and research other areas of life in addition to psychological well-being for both the caregiver and the person with spinal cord injury; the main focus will be on the impact of the well-being of the caregiver on the outcomes of the injured person.

Project Name

The Daily Activities of Caregivers Living with Disabled Persons

Project Description

This study will describe activities of wives and mothers in the transition of their sons or husbands with SCI into the home environment after discharge from medical care. It indicates the feasibility of using the SORT (Self-Observation and Report Technique) for measuring the impact of SCI on the caregiver in future studies.

Baylor College of Medicine

Center Publications:

No publications were directly provided to the Beach Center.

Rehabilitation Research & Training Center on Supported Employment

Virginia Commonwealth University
Box 2100, 1314 W. Main Street
Richmond, VA 23284-2011
(804) 367-1851

Project Director: Paul Wehman, Ph.D.
Research Director: John Kregel, Ed.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 5/1/88 - 4/30/93

Center Description

The mission of the Virginia Commonwealth University Rehabilitation Research and Training Center (VCU-RRTC) is to provide research, training, and leadership related to the supported employment of citizens with developmental and other severe disabilities.

Project Name

The Effect of Various Parent Educational Strategies on Parents' Knowledge of
Pref. for & Satisfaction with Support Employment Services

Project Description

The purpose of this study is to investigate the effects of training and information that parents of individuals with severe disabilities receive about transition from school to work. This is being done in cooperation with PEATC (Parent Educational Advocacy Training Center).

Rehabilitation Research & Training Center on Supported Employment
Center Publications:

No publications were directly provided to Beach Center.

Rehabilitation Research & Training Center on Severe Traumatic Brain Injury

Virginia Commonwealth University, Medical College
Box 434, MCV Station
Richmond VA 23298-0434
(804) 786-0200

Project Director: Jeffrey S. Kreutzer, Ph.D.
Research Director: Jeffrey S. Kreutzer, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 4/1/88 - 3/31/93

Center Description

The Center conducts relevant research & training on diagnosis and rehabilitation of persons with severe traumatic brain injury. Research includes investigations of hydrocephalus, pathophysiology of brain function, coma, memory disorders, family reactions to injury, outcome in children, & strategies for improvement of vocational outcomes. Training projects include development & collection of materials for inclusion in a National Clearinghouse of Information and specialized training programs relevant to TBI for multidisciplinary training professionals.

Project Name Family Research Project

Project Description

The primary purpose of this project is to provide longitudinal information regarding family needs and reactions to brain injury. Objectives include assessment of changes in family perceptions of needs over time; the extent to which primary caregivers report significant levels of psychological distress at different times post-injury.

Rehabilitation Research & Training Center on Severe Traumatic Brain Injury

Center Publications:

1. Kreutzer, Camplair, & Waaland. (1988) Family needs questionnaire.

Rehabilitation Research & Training Center

Consortium on Aging & Developmental Disabilities

**Walsman Center
University of Wisconsin-Madison
Madison, WI 53705
(608) 263-2966**

Project Director: Gary Seltzer, Ph.D.
Research Director:

Funding Agency: No information provided.

Funding Period: No information provided.

Center Description

The Wisconsin section of the initial NIDRR proposal was written with the intent of investigating the psychosocial and health status of caregivers of older persons with developmental disabilities.

**Project Name
First**

Project Description

This project is a short-term support and educational interventional targeted to enhancing the quality of relationships that families and other caregivers have with their formal and informal social supports.

**Project Name
Second**

Project Description

This project includes a diagnostic clinic for aging persons with developmental disabilities.

**Project Name
Third**

Project Description

This project is a collaborative one on aging families with sons or daughters with mental retardation.

Rehabilitation Research & Training Center

No publications were directly provided to the Beach Center.

Brown University

Rhode Island Hospital

**Department of Psychiatry and Medicine
Providence, RI 02903**

Project Director: Duane S. Bishop, M.D.
Research Director:

Funding Agency: Numerous private foundation grants.
Funding Period:

Center Description

See project descriptions.

Project Name

Multi-Center Stroke Study: Family Functioning, Health Status, Morale & Functional Capacity in Stroke Patients

Project Description

This study looks at the levels of family functioning, health status, morale and functional capacity in stroke patients and their families at four sites. All sites use a standardized protocol.

Project Name

Parkinsonism: Family Functioning, Functional Capacity, Depression and Health Status

Project Description

Family functioning, functional capacity, morale and health status data are being gathered on a population of Parkinson Disease patients and their spouses. These findings will be compared to data on patients with strokes.

Project Name

Male and Female Differences in Perception of Family Functioning

Project Description

This study compared couples with no illness, couples with one member in the family having a psychiatric illness and couples with one family member having a chronic illness or disability as to whether or not a husband and wife identify the same issues when asked to describe or reflect on the family.

Project Name
Family Functioning and Suicidality

Project Description
This study focuses on patients with major depression and on psychosocial correlates of suicidality. It discussed whether or not there are differences in family functioning between families of suicidal family and nonsuicidal depressed inpatients.

Project Name
Family Functioning: Reliability Validity

Project Description
This instrument is undergoing psychometric assessment.

Brown University

Center Publications:

1. Bishop, D.S., Epstein, N.B., Keitner, G.I., Miller, I.W., & Ryan, C.E. (1989). Family research program bibliography. Providence, RI: Family Research Program.
2. Videos:
 - McMaster Model of Family Functioning (1 hour)
 - Problem-Center Systems Therapy (3/4 hour)
 - Disability and the Family (1 hour)
 - Family Assessment (1 hour)
3. Family Instruments
 - McMaster Family Assessment Drive
 - McMaster Clinical Rating Scale
 - McMaster Structured Interview of Family Functioning
 - Manual for McMaster Problem Solving Systems Therapy of the Family

Illinois UAP

1640 West Roosevelt Road
Chicago, IL 60608
(312) 413-1537

Project Director: Tamar Heller
Research Director: Tamar Heller, Lou Rowitz, Bernard Farber

Funding Agency: National Institute of Child Health & Human Development
Funding Period: 1987-90

Center Description

See project description.

Project Name Domestic Cycle Project

Project Description

This project is designed to investigate relationships between families who have family members with mental retardation relative to families without members with mental retardation.

Project Name Transition Plan for Person with Developmental Disabilities Residing in the Natural Home with Elderly Parents

Project Description

The purpose of this project was to develop a plan for these adults by assessing the needs and attitudes of families and by examining related service system and policy issues.

Project Name Transition for Older Adults with Developmental Disabilities: Facilitating Family and Resident Adjustment

Project Description

This project will examine the major concerns of families and residents undergoing transitions to identify guidelines for lessening any trauma or crisis.

Illinois UAP

Publications:

1. Heller, T., & Factor A. (1988). Permanency planning among black and white family caregivers of older adults with mental retardation. Mental Retardation, 26(4), 203-208.
2. Heller, T., Bond, M., & Braddock, D. (1988). Family reactions to institutional closure. Mental Retardation, 92(4), 336-343.

Center Publications:

1. Heller, T., & Factor, A. Transition plan for persons with developmental disabilities residing in the natural home with elderly parents.
2. Heller, T., & Factor, A. GPCDD transition plan study: Interview plan study.
3. Rowitz, L., Heller, T., & Farber, B. Domestic cycle project: Primary caregiver interview.

New York University Medical Center
Department of Rehabilitation Medicine
400 East 34th Street
New York, NY 10016
(212) 340-6185

Project Director: Leonard Diller, Ph.D.
Research Director: Thomas Kay, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 1988 - 1992

Center Description

See project description.

Project Name

(Hi-Fi) The New York University Head Injury Family Interview: A Multi-Center Study

Project Description

The Hi-Fi was originally developed to meet the need for an interview that would comprehensively gather information about the specific issues relevant to TBI that would be useful to the clinician in an applied setting. The new version includes new sections on friendship and intimacy as well as on demographic and pre-injury data.

New York University Medical Center
NYU Research & Training Center for Head Trauma and Stroke

Center Publications:

1. Kay, T., Cavallo, M., & Ezrachi, O. The New York University head injury family interview. New York: New York University Medical Center, Research and Training Center on Head Trauma and Stroke.
2. Kay, T., Cavallo, M., & Ezrachi, O. (1988). Head injury family interview: Follow up interview, Version 1.2. (Report No. G008300039). New York: New York University Medical Center, Research and Training Center on Head Trauma and Stroke.
3. Kay, T., Cavallo, M., & Ezrachi, O. (1988). Head injury family interview: Significant Other interview, Version 1.2. (Report No. G008300039). New York: New York University Medical Center, Research and Training Center on Head Trauma and Stroke.
4. Kay, T., Cavallo, M., & Ezrachi, O. (1988). Head injury family interview: Survivor interview, Version 1.2. (Report No. 008300039). New York: New York University Medical Center, Research and Training Center on Head Trauma and Stroke.
5. Kay, T., Cavallo, M., & Ezrachi, O. (1988). Head injury family interview: Impact on the Family, Version 1.2. (Report No. 008300039). New York: New York University Medical Center, Research and Trauma Center on Head Trauma and Stroke.
6. Kay, T., Cavallo, M., & Ezrachi, O. (1988). Head injury family interview: Demographic and Pre-Injury Form, Version 1.2. (Report No. 008300039). New York: New York University Medical Center, Research and Trauma Center on Head Trauma and Stroke.

Oregon State System of Higher Education

Teaching Research Division

345 North Monmouth Avenue
Monmouth, OR 97361
(503) 838-1220

Project Director: H.D. 'Bud' Fredericks
Research Director:

Funding Agency: No information provided.
Funding Period:

Center Description

See project description.

Project Name
Foster Parent Training

Project Description

The assessment instruments have been developed for use with parents to assist them when they go to IEPS or for transition planning for work.

Oregon State System of Higher Education

Publications:

1. Fredericks, B., & Evans, V. (1987). Functional Curriculum. In Nelson, Rutherford, & Wolford (Eds.), Special education in the criminal justice system. Merrill.
2. Kraus, D., & Fredericks H. (1987). In Nelson, Rutherford, & Forness (Eds.), Severe behavior disorders of children and youth. College Hill Press.

Center Publications:

1. Teaching Research Publications Catalog
2. Nishioka-Evans, V., Hadden, C., Kraus, D., Johnson, J., Fredericks, H., & Toews, J. (1983). The teaching research curriculum for mildly and moderately handicapped adolescents and adults: Taxonomy and assessment. Monmouth, OR: Teaching Research Division.
3. Petersen, J., Trecker, N., Egan, I., Fredericks, H., & Bunse, C. (1983). Teaching research assessment procedures for the secondary student with severe handicaps. Monmouth, OR: Teaching Research Division.

Early Childhood Special Education

School of Education & Human Development

State University of New York-Binghamton
Binghamton, NY 13901
(607) 777-2727

Project Director: Christine Salisbury, Ph.D.
Research Director:

Funding Agency:
Funding Period:

Center Description

No description included.

Project Name
No projects listed.

State University of New York at Binghamton

Publications:

1. Rainforth, B., & Salisbury, C. (1988). Functional home programs: A model for therapists. Topics in Early Childhood Special Education, 7(4), 33-45.
2. Salisbury, C. (in press). Construct validity of the adapted questionnaire on resources and stress-short form. American Journal of Mental Retardation.
3. Salisbury, C. (in press). Family participation in communication intervention programs. In M. Wilcox & P. Campbell (Eds.), Communication programming from birth to three: A handbook for public school professionals. Boston: Little-Brown (in press).
4. Salisbury, C., & Intagliata, J. (no date). Respite care: Support for persons with developmental disabilities and their families. Baltimore: Paul Brookes.
5. Salisbury, C. (no date). Parenthood and the need for respite. (pp. 3-28).
6. Salisbury, C. (1987). Stressors of parents with young handicapped and nonhandicapped children. Journal of the Division for Early Childhood, 11(2), 154-160.
- Salisbury, C. (1986). Adaptation of the questionnaire on resources and stress-short form. American Journal of Mental Deficiency, 90(4), 456-459.
8. Vincent, L., & Salisbury, C. (1988). Changing economic and social influences on family involvement. Topics in Early Childhood Special Education, 8(1), 48-59.
9. Vincent, L., Salisbury, C., Strain, P., McCormick, G., & Tessier A. (in press). A behavioral-ecological approach to early intervention: Focus on cultural diversity. In S. Meisels & J. Shonkoff (Eds.), Handbook of early intervention. Cambridge University Press.

Center Publications:

1. Salisbury, C. (1984). Questionnaire on resources and stress-short form (adapted).

Center for Research on Teaching & Learning

University of Arkansas-Little Rock
2801 South University Avenue
Little Rock, AR 72204
(501) 569-3422

Project Director: Robert H. Bradley, Ph.D.
Research Director: Robert H. Bradley, Ph.D.

Funding Agency: Office of Special Education Research
Funding Period: 1983-86 & 1986-89

Center Description

See project description.

Project Name

The Usefulness & Validity of the HOME Inventory as Applied to Families with
Disabled Members

Project Description

This project reports on psychometric and descriptive information about the use
of the HOME Inventory when administered to families having children with
disabilities.

Center for Research on Teaching & Learning

Center Publications:

1. Bradley, R., Brisby, J.A., Caldwell, B.M., & Rock, S. The use of the home inventory for families with handicapped children. Little Rock, AR: University of Arkansas, Center for Research on Teaching and Learning.

University of California-Los Angeles

Department of Psychology
1285 Franz Hall
Los Angeles, CA 90024-1563
(213) 825-9176

Project Director: Bruce L. Baker, Ph.D.
Research Director:

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 10/01/86 - 09/30/89

Center Description

See project description

Project Name

Parent Training: Media-Based Versus Professionally Led Training

Project Description

Sixty-five families were randomly assigned to media-based training, the same curriculum with a professional leader, or a delayed-training control condition. Media-based programs may be a cost-effective way to make parent training more widely available.

University of California-Los Angeles, Department of Psychology

Publications:

1. Baker, B. (1988). Evaluating parent training, Irish Journal of Psychology, 9, 324-345.
2. Baker, B. L. & Blacher, J. (no date). Family involvement with community residential programs. In M.P. Janicki, M.W. Krauss, & M.M. Seltzer (Eds.), Community residences for persons with developmental disabilities: Here to stay. Baltimore: Paul H. Brookes Publishing Company.
3. Baker, B. & Clark, D. (1988). Intervention with parents of children with mental retardation. In S. Landesman, P. Vietze, & M. Begarb (Eds.) Living environments and mental retardation. American Association of Mental Retardation.
4. Kashima, K., Baker, L., & Landen, J. (1988). "Media-based versus professionally led training for parents of mentally retarded children", American Journal on Mental Retardation, 93(2), 209-17.

UCLA Clinic for the Behavioral Treatment of Children

University of California-Los Angeles

Department of Psychology
405 Hilgard Avenue
Los Angeles, CA 90024-1563
(213) 825-2319

Project Director: O. Ivar Lovaas, Ph.D.
Research Director: O. Ivar Lovaas, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 3/1/88 - 2/28/93

Center Description

No description provided.

Project Name

The impact of intensive behavioral intervention on families of preschool-aged artistic children.

Project Description

The intervention consists of approximately 40 hours per week of in-home one-to-one treatment for one to three years.

Project Name

Intensive Behavioral Treatment for Young Developmentally Delayed Children

Project Description

This investigation is intended to enhance intellectual, educational and social skills of young developmentally delayed children so they can take better advantage of the educational opportunities provided for them in the public schools.

UCLA Clinic for the Behavioral Treatment of Children

Center Publications:

No publications were directly provided to the Beach Center.

University of California-Santa Barbara

Department of Speech and Hearing Sciences
Santa Barbara, CA 93106

Project Director: Robert L. Koegel, Ph.D.
Research Director:

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 9/30/86-9/30/89

Center Description

See project description.

Project Name Study in Progress

Project Description

The purpose of this study was twofold: to extend research on stress in parents of children with autism and to compare the results of this research with established normative data.

University of California - Santa Barbara

Publications:

1. Koegel, R., Schreibman, L., Johnson J., O'Neill, R., & Dunlap, G. (1984). Collateral effects of parent training on families with autistic children. In R.F. Dangel & R.A. Polster (Eds.), Parent training foundations of research and practice. New York: Guilford Press.
2. Koegel, R., Schreibman, L., O'Neill, R., & Burke, J. (1984). The personality and family-interaction characteristics of parents of autistic children. Journal of Consulting and Clinical Psychology, 51(5), 683-692.
3. Schreibman, L., Koegel, R., Mills, D., & Burke, J. (1984). Training parent-child interactions. In E. Schopler & G. Mesibov (Eds.) The effects of autism on the family. New York: Plenum.

Center Publications:

1. Koegel, R., Schreibman, L., Good, A., Cerniglia, L., Murphy, C., & Koegel, L. (no date). How to teach pivotal behaviors to children with autism.

Institute for Research in Learning Disabilities

The University of Kansas
230 Carruth O'Leary Hall
Lawrence, KS 66045
(913) 864-4780

Project Director: Don Deshler, Ph.D.
Research Director:

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 10/86 - 9/89

Center Description

See project description.

Project Name

The Development and Evaluation of an Intervention Program for Families with
Learning Disabled Youth

Project Description

The goal of this project is to develop and evaluate a program for families with children with learning disabilities by identifying family needs and the development of program materials and instructional procedures to address these needs.

Institute for Research in Learning Disabilities

Center Publication:

1. Walther-Thomas, C., Hazel, J.S., Schumaker, J.B., Vernon, S. and Deshler, D.D., A Program for Families with Children with Learning Disabilities (no date given)

The University of North Carolina at Chapel Hill

Frank Porter Graham Child Development Center

CB #8080, Highway 54 Bypass West
Chapel Hill, NC 27559
(919) 966-1703

Project Director: Sharon Landesman, Ph.D.
Research Director:

Funding Agency: No information provided.
Funding Period:

Center Description

See project description. (Some research done with Dr. Melly Reid at the University of Washington.)

Project Name

My Family and Friends: 6 to 12 Year Old Children's Perceptions of Social Support

Project Description

This was an evaluation of the instrument, 'My Family and Friends,' used to study children's subjective impressions about social support.

The University of North Carolina at Chapel Hill:
Frank Porter Graham Child Development Center

Publications:

1. Landesman, S. (1986). Toward a taxonomy of home environments. International Review of Research in Mental Retardation, 14, 259-289.
2. Landesman, S., Jaccard, J., & Gunderson, V. (no date). The family environment: The combined influence of family behavior, goals, strategies, resources, and individual experiences. To be published in M. Lewis & S. Feinman (Eds.), Social influences on development. NY: Plenum.
3. Reid, M., Landesman, S., Treder, R., & Jaccard, J. (in press). My family and friends: 6-12 year old children's perceptions of social support. Child Development.

Center Publications:

1. Child Instruments
 - My Family and Friends, Part 1
 - My Family and Friends, Part 2
 - What I'm Like and What I Think About Others in the Family
 - What is Important in My Family
 - Ways to Get Chores Done in My Family
 - Ways My Family Helps Me with School
 - Young Person's Opinion of Family Size and Education
2. Adult Instruments
 - Assessment and Description of Family Life
 - Assessment of Parenting Skills
 - Assessment of Individual Family Members and Relationship Within the Family
 - Tools to Assess Parents' Personality, Mood, & Health

Specialized Training Program

Family Issues Group

University of Oregon
135 Education
Eugene, OR 97403
(503) 686-5311

Project Director: Philip Ferguson
Research Director:

Funding Agency: Office of Special Education & Rehabilitation Services
Funding Period: 1987-90

Center Description

See project description.

Project Name
Parents' Graduation Alliance

Project Description

This project provides support to families of students with severe disabilities as they face the transition from school to work and adult life.

Project Name
Parent/Professional Graduation Alliance

Project Description

This project, built on the previous project, provides support and training to families whose deaf-blind children are leaving school and going to adult life.

Specialized Training Program

Publications:

1. Ferguson, P., Ferguson, D., & Jones, D. (1987). Generations of hope: Parental perspectives on the transition of their severely retarded children from school to adult life. In P. Ferguson (Ed.), Transition planning and adult services: Perspectives on policy and practice, Eugene, OR: Specialized Training Program.
2. Ferguson, P., & Ferguson, D. (1987). Parents and professionals. In P. Knoblock, Understanding exceptional children. Boston: Little Brown.
3. Ferguson, P., Ferguson, D., & Jones, D. (1988). Generations of hope: Parental perspectives on the transitions of their children with severe retardation from school to adult life. JASH, 13(3), 177-187.
4. Ferguson, P., & Asch, A. (In press). Lessons from life: Personal and parental perspectives on school, childhood, and disability. In D. Biklen, D. Ferguson, & A. Ford (in press), Schooling and disability. 1989 Yearbook of the National Society for the Study of Education.
5. Slovic, R., Ferguson, D., Ferguson, P., & Johnson, C. (1987). GUIDES: Aid transition for severely handicapped children. Teaching Exceptional Children, 20(1), 14-18.

Center Publications:

1. Family Transition Planning and Support System
2. Human Subjects Activity Review Form
3. Parents Graduation Alliance: Transition Support for Severely Handicapped Students
4. Parent Primer (1988)

University of Pittsburgh

Western Pennsylvania School for the Blind

201 N. Bellefield Avenue
Pittsburgh, PA 15213-1499
(412) 683-5960

Project Director: Robert T. Ammerman, Ph.D.

Research Director: Robert T. Ammerman, Ph.D.

Funding Agency: National Institute on Disability & Rehabilitation Research

Funding Period: 9/1/87 - 8/31/89

Center Description

See project description.

Project Name

Assessment and Treatment of Abuse and Neglect in Handicapped Children and Adolescents

Project Description

This project will examine the incidence of abuse and neglect in 150 consecutive admissions of with multiple disabilities hospitalized for psychiatric reasons. The project will then apply comprehensive behavioral treatment to 10 parents who have physically abused their children and 10 parents who have neglected their children.

Project Name

Dyadic Interactions in Parents of Visually Handicapped Adolescents: A Sequential Analysis

Project Description

This study contrasted the interaction patterns and psychological adjustment of 25 parents of adolescents with visual impairment with 25 parents of adolescents with spina bifida and 25 parents of adolescents without disabilities.

University of Pittsburgh

Publications:

1. Ammerman, R., Van Hasselt, V., & Hersen, M. (1988). Maltreatment of handicapped children: A critical review, Journal of Family Violence, 3(1), 53-72.
2. Van Hasselt, V., Ammerman, R., & Sisson, L. (1988). In A.E. Kazdin, A.S. Bellack & M. Hersen (Eds.) Physical Disability, International handbook of behavior modification and therapy, (2nd Ed.). New York: Plenum Press.
3. Ammerman, R. (in press). "Child abuse and neglect," Hersen, M. (Ed.) Innovations in child behavior therapy. New York: Springer.
4. Van Hasselt, V., Ammerman, R., Matsen, J. L. & Sisson, L. (1988). Sensory and Physical Handicaps, Handbook of Treatment Approaches in Childhood Psychopathology, New York: Plenum Press.
5. Ammerman, R., Lubetsky, M., Hersen, M., and Van Hasselt, V. (1988). Maltreatment of children and adolescents with multiple handicaps: Five case examples. Journal of the Multihandicapped Person, (2), 129-139.
6. Ammerman, R. (in press). Prevention of mother-child problems in families with young handicapped children. International Journal of Rehabilitation Research.
7. Ammerman, R., Hersen, M., & Lubetsky, M. (in press). Assessment and treatment of abuse and neglect in multihandicapped children and adolescents, International Journal of Rehabilitation Research.
8. Ammerman, R., Van Hasselt, V., Hersen, M., McGonigle, J., & Lubetsky, M. (in press). Child Abuse & Neglect.

Center Publications:

1. Ammerman, R., Hersen, M., Van Hasselt, V., Forster, J., & Simon, J., Behavioral and Psychiatric Consultation Services for Children with Visual Impairments and Multiple Disabilities in an Educational Setting: A Program Description, Grant No. G008720109.
2. Moore, L., Van Hasselt, V., Ammerman R., & Hersen, M., Recommendations for the Assessment and Treatment of Visually Impaired Adolescents and their Families, Grants No. G008300135 & G008720109, from the National Institute on Disabilities and Rehabilitation Research.

Human Services Research Institute

2336 Massachusetts Avenue
Cambridge, MA 02140
(617) 876-0420

Project Director: Valerie Bradley
Research Director: James Kroll

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 9/86 - 9/89

Center Description

See project description.

Project Name

Financing Home Care for Children with Chronic Illness & Severe Disabilities

Project Description

The purpose of this grant was to examine financing models for supporting children with severe disabilities and chronic illness so that they can live at home. One product is a technical assistance manual.

Project Name

Becoming Informed Consumers: A National Survey of Parents's Experience with Respite Services

Project Description

This project involved three major activities: establishment and utilization of a national advisory panel, an indepth review of literature on family supports, system change, and consumer empowerment as it relates to respite services, and national survey of parents.

Human Services Research Institute

Center Publications:

1. Knoll, J.A., & Bedford, S. Becoming informed consumers: A national survey of parents' experience with respite services, (Report No. RS88072003). Cambridge, MA: Human Services Research Institute.
2. Ellison, M.L., Bradley, V.J., Knoll, J., & Moore, K. (1988). Financing options for home care for children with chronic illness and severe disability: Technical assistance manual. Cambridge, MA: Human Services Research Institute.
3. Wells, A., Agosta, J., Berliner, S., Bradley, V., Cox, H., Nurczynski, P., & Bedford, S. (1987). Home care for children with chronic illness and severe disabilities: A bibliography and resource guide. (Report No. 133H70012), Cambridge, MA: Human Services Research Institute.)
4. Family interview protocol. (1988). Cambridge, MA: Human Services Research Institute.

New York State Head Injury Association

Office of the Executive Director
194 Washington Avenue
Albany, NY 12210
(518) 434-3037

Project Director: Betty Pieper
Research Director: Pamela G. Burns

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 10/88 - 10/91

Center Description

See project description. This project is subcontracted to the State University of New York at Buffalo.

Project Name

Model Family-Professional Partnership Interventions for Childhood Traumatic
Brain Injury Survivors

Project Description

This project deals with the social, psychological and economic impact of traumatic brain injury on families of children up to 16, with the goal of designing valid collaborative interventions for professionals and families at the critical stage of the restorative process.

New York State Head Injury Association

Center Publications:

1. Model Family-Professional Partnership Interventions For Childhood Traumatic Brain Injury Survivors- Abstract.

PEAK Parent Center, Inc.

6055 Lehman Drive, Suite 101
Colorado Springs, CO 80918
(719) 531-9400

Project Director: Barbara Buswell
Research Director: Barbara Buswell

Funding Agency: National Institute on Disability & Rehabilitation Research
Funding Period: 9/1/87 - 8/30/88

Center Description

See project description.

Project Name

Discover the Possibilities: Integration Curriculum for Parents

Project Description

Through this project, PEAK will utilize the parents training parents model to develop and pilot a curriculum in workshop format. It will then be distributed by parent training and information centers to other parent groups who wish to offer it to families in their state or area.

Project Name

Parents and Integration: Reclaiming the Vision

Project Description

The intended outcome of this project is that parents whose children receive special education services will be enabled to reclaim their visions for their children and will have resources to advocate for their sons and daughters to be more fully integrated in school and community life.

PEAK Parent Center, Inc.

Center Publications:

1. Brochure, Master New Possibilities: Peak Integration Project
2. Brochure, PEAK
3. Brochure, (in Spanish)
4. SPEAK OUT (newsletter, 3 times annually)
5. SPEAK OUT Reprint Series
 - Finding the doctor who is right for you
 - Getting Help when you need it-Counseling
 - Will Your Child Be Putting on a Cap & Gown?
 - Watch Your Language
 - Meeting Children's Unique Needs: Teachers Who Do It
 - How Can Parents Be Good Partners?
 - Now Possibilities emerge for Special Education
 - A Powered Wheelchair for your child?
 - Getting Ready to Go for a staffing
 - Seizures in Children
 - Selecting a Private PT or OT
 - Whys and Hows of choosing a Preschool
6. Starting a Parent Support Group
7. Switchback: Looking Ahead & Looking Back
8. Intergration
9. PEAK calendar, 3/89

TEACCH Program

The University of North Carolina-Chapel Hill

CB #7180, 310 Medical School Wing E
Chapel Hill, NC 27599
(919) 966-2173

Project Director: Gary B. Mesibov, Ph.D.
Research Director:

Funding Agency:
Funding Period:

Center Description

See project description.

Project Name

Fathers Present/Fathers Absent Project

Project Description

This study compared the extent to which the presence of a young male child with or without developmental disabilities affected adaptation and family roles for both mothers and fathers.

Project Name

Mothers of Children with Autism or Communication Disorders

Project Description

This study demonstrates the effectiveness of a modified Double ABCX model in predicting successful adaptation in 45 families of children with autism and communication disorders.

TEACCH Program

Publications:

1. Bristol, M., & Gallagher, J. (1983). Psychological research on fathers of young handicapped children: Evolution, review, and some future directions. In J.J. Gallagher & P. Vietze (Eds.), Families of handicapped children. Baltimore: Paul Brookes.
2. Bristol, M. (1987). Mothers of children with autism or communications disorders: Successful adaptation and the double ABCX model. Journal of Autism and Developmental Disorders, 17(4), 469-486.
3. Bristol, M., Gallagher, J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. Developmental Psychology, 24(3), 441-451.
4. Schopler, E., & Mesibov, G. (1984). Professional attitudes toward parents: A forty-year progress report. In E. Schopler & G.B. Mesibov (Eds.), The effects of autism on the family (pp. 3-17). Plenum.
5. Schopler, E., Mesibov, G., Shigley, R., & Bashford, A. (1984). Helping autistic children through their parents: The TEACCH model. In E. Schopler & G.B. Mesibov (Eds.), The effects of autism on the family (pp. 65-81). Plenum.

Center Publications:

1. Publications list

Through the Looking Glass

801 Peralta Avenue
Berkeley, CA 94707
(415) 525-8138

Project Director: Megan Kirshbaum, Ph.D.
Research Director:

Funding Agency: NIDRR, and Easter Seal Research Foundation 1985-88
Funding Period: 1985-88

Center Description

'Through the Looking Glass' orientation is to formulate research questions and priorities as an outgrowth of longterm clinical experience with families with disability issues, and based on the personal/family experience of its dual peer/professional staff and clientele. Emphasis is on parents with disabilities, and they have worked with more than 125 families with at least one parent with a disability.

Project Name Bridges

Project Description

The purpose was to develop a service model for parents with disabilities.

Project Name Through the Looking Glass

Project Description

This project resulted in the development of a training package for professionals concerning families and babies with disability issues in EITHER baby or parent.

Project Name Through the Looking Glass

Project Description

This project focused on demonstrating via videotape how experienced parents with disabilities could teach expectant or new parents various techniques, adaptive strategies or equipment modifications.

Through the Looking Glass

Publications:

1. Kirshbaum, M. (1988). Parents with physical disabilities and their babies. Zero to Three, 8(5), 8-14.

Center Publications:

1. Parenting with a Disability, biannual newsletter

FEEDBACK

WE WOULD LIKE TO HEAR FROM YOU.

CENTER (OR PROJECT) TITLE -

ADDRESS -

CITY, STATE, ZIP -

PHONE - ()

DID THIS BOOKLET DESCRIBE YOUR CENTER OR PROJECT(S) CORRECTLY?

IF NOT, WHAT IS THE DESCRIPTION YOU PREFER?

WERE THE PUBLICATIONS YOU MAILED US LISTED CORRECTLY?

IF NOT, WHAT IS THE CORRECT LISTING?

WAS THE INFORMATION IN THIS BOOKLET USEFUL TO YOU?

WHAT WOULD YOU LIKE TO SEE INCLUDED IN FUTURE BOOKLETS?

ATTACH ADDITIONAL SHEETS FOR INFORMATION THAT DOES NOT FIT ON THIS PAGE.

Thank you for your feedback.

Beach Center on Families and Disability
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